

**Many Voices.
Unique Needs.
One Vision.**

CURING CANCER THROUGH VHL RESEARCH

A letter from our executive director

It is exciting to be entering a new phase and journey in my career. Please allow me to introduce myself. I am Janet Thompson, and I am honored to have been selected to serve as the Executive Director for the VHL Alliance. Tackling my first month in the role as Executive Director has been equal parts exhilarating and demanding. From meeting with world-class medical professionals to diving deep into the programs, research, support, and education that the VHLA provides to meeting and interacting with both patients and families, I am energized by the opportunities that lie ahead. Working together, I look forward to exploring new opportunities, developing partnerships that will sustain the future of the Alliance, and fostering relationships that will carry us forward for years to come.

Far and away, the most rewarding activity of the last few weeks has been personal engagement with individual VHL patients and caregivers, both in person and virtually. Prior to starting I dove right in and had the opportunity to attend the Julie Flynn Hope Young Adult Retreat in Washington, D.C. This was an amazing opportunity to see the power of bringing together VHL patients, build upon shared experiences, connect with VHL clinicians, and foster a community of shared support and encouragement for the future. Events like this perfectly represent the heartfelt purpose of the VHL Alliance and underscores the reason it is such an honor to join this community.

I do not have VHL, nor does anyone in my family. While I do not have the shared perspective of direct VHL impact, I can draw upon my experiences and perspectives to inform our work.

I am the mother of a son with Down Syndrome - I do understand receiving news of a diagnosis that will significantly change my child's and family's life. I know the pain and struggle, but also find empowerment and support in community - a community of fellow travelers found my family and me, lovingly helped us navigate the journey, and our lives have been fully blessed by it. In much the same way, I find this spirit in the VHL community. This is what drew me to the organization, this community, and what inspires me to serve with you every day.

As we move forward, we will continue to build upon the success of the past while also looking at the opportunity to put together programs of value for our community into the future. Our advocacy, research, and clinical teams continue their tireless efforts of securing resources to improve health outcomes and to find a cure. Our annual VHL Awareness Month in May is on the horizon to emphasize the importance and impact of sharing patient stories, building awareness and education, and ensuring support and progress for our community. The Annual Family Weekend is scheduled for August in Nashville in conjunction with Vanderbilt University and will highlight the strength of our community and our collective commitment to our mission.

Looking forward, I am equally honored and confident to take the helm and advance our mission fully. Together, we can radically improve outcomes for VHL & cancer patients alike. I look forward to serving our community this year and beyond!

Janet Thompson

Young Adult Retreat

In February, seventeen young adults with VHL arrived in our nation's capital for a chance to socialize, learn, share, and support one another during the Julie Flynn Hope Retreat for Young Adults. Many attendees had never met someone with VHL outside of their immediate family. Participants met with and learned from some of the top doctors in the field of VHL research from the National Institutes of Health - Dr. Marston Linehan and Dr. Ram Srinivasan of the National Cancer Center, and Dr. Emily Chew of the National Eye Institute. Additionally, participants built community by touring Washington, D.C., dining and cooking together, and forging new friendships. An informal, yet enriching question and answer session allowed for open and honest discussions around the current challenges of living with VHL while sharing the hope of recent therapies and breakthroughs.

"Being able to connect with other people in the VHL community was life changing. We shared how we've felt alone in facing VHL. Not anymore. VHL Warriors are truly one of a kind! I can't wait until next year."

Emily Larson

Julie Flynn Hope
Retreat Participant



May Awareness Month

May is our annual VHL Awareness Month. Help us build awareness by sharing your VHL story!

There are a number of ways to build momentum and educate others about VHL and we need your help. This year, we're asking our community to share their VHL stories on social media. By sharing your VHL story, you can help our cause gain traction, build awareness, and educate others about our condition, progress, and achievements. To participate in the awareness month movement please use the hashtag #vhlawareness

Don't forget to tag our social media channels, too!

Social media isn't the only way to get involved. You can also:

- Host a fundraising event
- Fill out surveys on the MyVHL platform to support VHL research at vhl.org/myvhl
- Encourage friends and family to like and share our content

Get ready for an email story series kicking off on May 1st! If you haven't already, you can join our mailing list at vhl.org/newsletter



@VHLAlliance



@vhl_alliance

Advocacy

The VHL community has many advocacy wins to celebrate! The FY23 Federal Budget passed with two opportunities for VHL research funding through the Congressionally Directed Medical Research Program (CDMRP). Additionally, VHL researchers are able to apply for research funding in the Peer Reviewed Cancer Research Program (PRCRP) and the Peer Reviewed Medical Research Program (PRMRP). Together, these programs provide opportunities to fund groundbreaking research and new treatments for VHL. Every cent brings us closer to our vital mission: Curing Cancer Through VHL Research.

Even with great wins, there is always more work to do and progress to make...

In March, eighteen members of the VHL community met with congressional offices through our partner organization KidneyCan. In these meetings, volunteers shared their stories with members of Congress and emphasized the importance of research funding for patients and caregivers alike. We have also worked to secure the support of Senators Markey (MA) and Booker (NJ) to continue VHL's research funding eligibility in the PRMRP for FY24. Currently, our dedicated advocacy team is working to recruit more champions in the Senate and ensure the continuation of this funding. Our success would be impossible without our fantastic volunteer advocates.

Interested in getting involved? Visit vhl.org/advocacy to learn more!

Upcoming Events

Monthly Community Calls

Our monthly call groups for patients, caregivers, low/no vision community members, and parents of VHL patients continue to gain momentum and build community. If you'd like to join the mailing list for the calls please visit vhl.org/events

Virtual Tumor Board

Private Event

The VHLA Tumor Board is made up of VHL experts who are actively involved in VHL research and patient care. This monthly call allows researchers and clinicians to receive feedback and share their experiences with treating VHL patients, with particular emphasis on Welireg (Belzutifan) outcomes.

VHLA Family Weekend

August 4-6, 2023

We couldn't be more excited about this year's family weekend hosted by Vanderbilt University in Nashville, TN. With a fully revamped schedule and ample opportunities to connect with other families in the VHL community, this year's family weekend can't be missed! More details on the event schedule, hotel, and registration coming soon.



Research

One of the pillars and priority areas of work of the VHLA is funding research projects with potential to positively impact the VHL community. After a rigorous application cycle, we are excited to announce the funding of three new 2023 research projects awarded to Dr. Samra Turajlic from the Francis Crick Institute (UK), Dr. Mei Yee Koh from the University of Utah (US), and to Dr. Reut Halperin from the ENTIRE Research Center in Israel.



Dr. Turajlic's project is entitled "Investigating Tissue-specific VHL Haploinsufficiency and Tumorigenesis with Patient-Derived iPSC."

While patients with VHL can develop tumors in different organs, the affected organs in each individual can vary, which correlates to specific inherited *VHL* gene mutations. However, the particular mutations that lead to the development of certain tumors are not well understood. Therefore, Dr. Turajlic and her team aim to understand how the germline *VHL* mutations in individual VHL patients lead to tumor formation in specific organs. This team hopes this project will lead to a better understanding of how certain VHL patients develop particular VHL-associated tumors while others do not, in an effort to provide insight into how to stop the development of tumors in certain VHL-affected tissues.



Dr. Koh's project is also investigating specific tumor types seen in VHL patients and is entitled "Neurofibromin stabilization as a treatment strategy for VHL disease."

A type of kidney cancer, clear cell renal cell carcinoma (ccRCC) is a major cause of death in patients with VHL.

This team aims to understand how neurofibromin loss can lead to cancer growth and perform a screening to identify molecules that can prevent neurofibromin loss. They hope that this research can help to identify new therapies that can prevent neurofibromin loss as a potential treatment method for VHL disease.

Dr. Halperin's pilot grant project is examining VHL-associated tumors and is entitled "Assessing a possible association of synonymous germline VHL variants with VHL-related neoplasm prevalence and metabolic alterations – A Large-scale UK BIOBANK-based cohort study."



Some genetic alterations in the *VHL* gene can lead to the formation of tumors in various parts of the body, in addition to changes in metabolism.

However, other changes in the *VHL* gene are considered to be low risk. Therefore, this project aims to investigate whether these low-risk changes in the *VHL* gene are associated with VHL disease-related tumors and metabolic differences in a large patient population. Dr. Halperin and her team will use the UK Biobank database to compare clinic data between patients with and without these low-risk alterations in the *VHL* gene, in hopes of gaining a better understanding of the potential differences in risks of VHL-related cancers and metabolic alterations in those with and without genetic *VHL* mutations.

These projects, coupled with the work in progress and completed previously, stand to assist in making strides toward treatments, a cure, and improving the quality of life for VHL patients and the community.

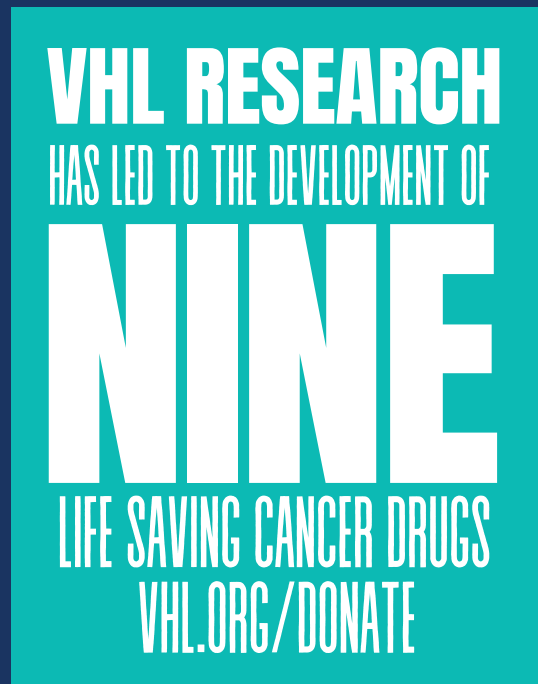
We can't achieve our mission without your support.

Curing cancer through VHL research is a lofty goal. This is why we need your help! We are seeking support from businesses, colleagues, families, and friends. It takes us all!

You can show your support in a variety of ways:

- Making a donation via the enclosed envelope or at vhl.org/donate
- Participating in VHL Awareness Month by posting with the [#vhlawareness](https://twitter.com/vhlawareness) hashtag
- Hosting a personal fundraiser with friends and family
- Sharing your story on social media and spreading the word about our cause - make sure to ask for the support and contributions of others
- Leveraging corporate matching or giving
- Asking your employers to make a donation
- Be creative - there are so many ways to support the work of the VHLA!

With your help, we've grown from a small community organization to an internationally respected leader in the cancer research community. This work is not possible without your help. Thank you!



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